What to do when a marginalized patient denies HIV status

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It's appropriate for physicians to want to initiate lifesaving antiretroviral therapy (ART) for patients with HIV, but when a patient is in denial of his diagnosis, a physician may be tempted to initiate ART and other potentially lifesaving therapies by any means necessary—including deception.

An article published in the AMA Journal of Ethics® (@JournalofEthics) by Tim Lahey, MD, MMSc, director of ethics at the University of Vermont Medical Center and professor of medicine at the Robert Larner College of Medicine at the University of Vermont, examines this phenomenon through the lens of racial health inequities.

Using the hypothetical case of a 56-year-old Black man with HIV who is hospitalized with failure to thrive and dyspnea, the author explored how social factors can affect a patient’s perception of the disease and recommended a course of action for building an effective, and aboveboard, treatment plan. In the past, the patient has told physicians, “I don’t have HIV.”

Start by building trust

One of the foremost realities physicians need to keep in mind when treating patients with HIV is that the disease disproportionately affects marginalized populations.

The prevalence of HIV infection is higher in populations with specific sexual and drug-use behaviors, and awareness of this has often fueled discrimination and stigma among physicians—even the most well-meaning—who mistakenly make inferences about a patient’s mindset, behaviors or risks on the basis of these demographics.

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Patients, reasonably, react to this by feeling stigmatized, and they can end up even further alienated from family members, friends, employers, community leaders and health professionals who could have helped them.

Trust, therefore, “is central to therapeutic alliance and thus to the success of therapies like ART,” Dr. Lahey wrote, adding that Black and Latino patients, in particular, have suffered inequities that long predate the HIV epidemic. “HIV-related stigma and clumsy clinician assumptions can simply confirm patients’ preexisting mistrust and thus lead to their further ostracism from high-quality care.”

Never lie

Physicians’ temptations arising from positive motivations, “like the desire to save a life, can be the most difficult to resist,” Dr. Lahey wrote, noting that doctors might even want to initiate treatment without the patient’s full knowledge or consent.

But the bottom line is it’s never OK to deceive a patient in order to overcome his denial of his condition or his objection to a therapy.

“A lie today is not likely to save his life tomorrow and, in fact, it could have just the opposite effect,” Dr. Lahey wrote, noting that if a patient were to discover he is taking the therapy, his adherence to ART would falter and he would be unlikely to seek care in the future.

“Deceit itself could thus be lethal, converting a misguided attempt at beneficence into an act of maleficence,” he added.

Ask these questions

To identify knowledge gaps or attitudes that are obstructing a patient’s acceptance of ART, the physician might ask herself exploratory questions, such as:

- What are the patient’s goals of care? Is longer life one of them?
- Are there aspects of his health or HIV that he is willing to discuss?
- Are there words that the patient is comfortable using to address these topics?
- What does he understand about ART?
- Does the patient believe ART will prolong his life?
- Has he made any statements indicating he might be receptive to ART?
Upon getting a better understand of the patient’s wishes and needs, the physician will be in a better position to offer ART-adherence support by way of evidence-based interventions, such as cognitive behavioral therapy, directly observed therapy and dose reminders.

“Throughout these conversations,” Dr. Lahey wrote, the physician “should always be clear that the treatment she is offering is treatment for HIV.”

The May issue of the AMA Journal of Ethics further explores, in print and podcast, ending the HIV epidemic.